

Daughterhood the Podcast

Episode #45: How Palliative Care Empowers Decisions with Dr Caitlin Baran

• 50:28

Disclaimer 00:02

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Rosanne 00:43

Hello, and welcome to Daughterhood the Podcast. I am your host Rosanne Corcoran Daughterhood Circle leader and primary caregiver. Daughterhood is the creation of Anne Tumlinson who has worked on the front lines in the healthcare field for many years and has seen the multitude of challenges caregivers face. Our mission is to support and build confidence in women who are managing their parents care. Daughterhood is what happens when we put our lives on hold to take care of our parents. We recognize this care is too much for one person to handle alone. We want to help you see your efforts are not only good enough, they are actually heroic. Our podcast goal is to bring you some insight into navigating the healthcare system provide resources for you as a caregiver as well as for you as a person and help you know that you don't have to endure this on your own. Join me in daughter hood. Palliative care, the often misunderstood, underutilized yet empowering option in medicine. Today, my guest is Dr. Caitlin Baran, an internal medicine physician specializing in palliative care at the University of Vermont Medical Center in Burlington and Co Founder and Chief Medical Director of a piny MD. She also serves on the editorial board for the Journal of Palliative Medicine. Her clinical interests include palliative care and oncology and population community based palliative care. Above all else, Dr. Baron feels privileged to care for patients faced with serious illness, ideally working to help them live as well as possible. Today, we discuss the confusion over palliative care, helpful questions to ask your care partner and their providers and how palliative care can empower caregivers and their care partners. I hope you enjoy our conversation.

Rosanne 02:23

Palliative Care almost has a marketing problem as it's more presented from the medical system as you either choose treatment or you go over there into this whole other scary section that we can't tell you what they do. You'll have to speak to someone there when you get there. What is palliative care?

Caitlin Baran 02:40

Oh, it's such a mystery, isn't it for individuals living with illness and for caregivers for everybody? Yes, health care. So it's, you know, it's a team that helps to take care of individuals who are facing some sort

of serious illness, which what the heck is that? It's it's anything big, it's heart failure is cancer, it's ALS, any of these sort of notable diseases that are impacting you, as an individual or person as an individual. The palliative care team is there to provide an extra layer of support, in addition to the care team that people already have, the focus of palliative care is on improving quality of life. So managing symptoms, if they can to give people more good days, however, those look, and the other piece of it is helping to make sure that people actually get the kind of health care that they want, trying to align individual values with health care decisions and choices and plans of care. which is no small feat. But that's that's really what the team is there to do. So it's sort of kind of the most personalized version of health care. I think that's out there in ways.

Rosanne 03:50

Absolutely is, is it only for terminally ill patients, or can you choose it at any time? Like, you know, how when people are getting older, and they're like, I don't want any treatments? I don't want to you know, how do we access that?

Caitlin Baran 04:02

Absolutely. So no, you don't have to have a terminal illness. It's anybody who is aging, anybody who has some sort of illness. So really, it's kind of everybody overtime, right? We're all aging at some point, right? All the points. And so it is available to anybody, and you don't have to be in your final days or weeks or months. I think that's the beauty of it, you can get it actually in tandem with any of the other care that you're getting. So while getting cancer treatment while getting treatment for heart failure, while preparing for aging, and while navigating dementia, all of these all of these things,

Rosanne 04:41

Okay, because it's interesting and you know, dementia is always the outlier. Because I know I had called to say can we get palliative care and they're like, No, dementia isn't one of the options and I'm like, well, that doesn't even make sense to me because it is this chronic degenerative progressive disease. And I don't know if it was it was probably because there's so many people with dementia, how do you how do you handle all of that?

Caitlin Baran 05:07

Totally. So I think it kind of gets at the issue of access. Right. So palliative care, you know, in theory, it serves all of these patients. I think What's hard is, then that's, that's a vast number of people out there, right. And there are only so many palliative care providers, people go through extra training to be able to learn how to do this, to get these communications tools to get the skills to sort of manage these symptoms. So it is a small population of providers, it's also limited in just the availability depending on location that you are. And so programs, I think, have to create different guidelines, they have to sort of narrow the field that they do cover. So anything that you're naming is super common, especially in the outpatient setting, the sort of non hospitalized population, which is really, you know, the community, the community is the people who need it the most Yes. And yet, it's where this resource is often the most limited. So, you know, in theory, there are outpatient palliative care programs that are sometimes attached to a hospital organizations, and they are able to see patients living with a serious illness, however, with the way that funding is, and the way that the sort of scarcity of the resources, they're often actually connected with cancer centers, right, and are, they're really narrow in the patient

population that they're able to take on. So that's, you know, the free clinics. And then there's the home health, which sometimes there's a little bit more access to palliative care in that setting, sort of the visiting nurses. But even that can be pretty limited, you often have to have a skilled need, just the barrier that we always run into in the community, right, of getting more help in the home, if you don't have that skill need. And so there are actually also a few private sort of coaching companies, which is obviously one of the things that I do as well. But there's a few organizations that have basically seen that there is this sort of dearth of access to palliative care. And so trying to think about how do you actually bring that resource to more people? There are some sort of freestanding coaching or independent palliative care organizations that are out there. But it is you're totally right. It's something that should be so widely available to so many people. And for a variety of reasons. We just don't have enough of it.

Rosanne 07:35

No, and there's such a, there's so much misinformation about palliative care. And there's so many myths, like common myths that make people go oh, no, I can't do that. Oh, I don't want to. That's just the end of the road. Can you? Can you talk about some of those common myths?

Caitlin Baran 07:54

Yeah, for sure. You sort of alluded to at the beginning, it just has a bad rap. People sort of associated I think instinctively with hospice care, yes, end of life care. And I think even for hospice care in this country, we often think that that's the final hours or days or weeks even. And what I would say is palliative care and hospice care are different. It's a spectrum of care. hospice care is in the final months of life often. And it's focused more on comfort, whereas palliative care is about symptom relief, and providing sort of comfort and quality of life to people. But as I said before, it's in tandem. It can be with treatments, it can be with hospitalizations, it can be with you know, the pursuit for a cure for a disease even. It also can be for people who are getting sicker, who are nearing the end of their life, but I think people just hear it. And it's it's scary when you have that deep association with it being distinctly end of life care. And I think one of the other myths is that someone's going to persuade you to do something you don't want to do. talk you out of getting a treatment, talk you into into something else into a different plan of care. And what I would say is palliative care done well, is actually about figuring out what your agenda is not a provider's agenda or a healthcare systems agenda. It's trying to understand an individual's values and needs and really align that care with those needs. But who wouldn't want that?

Rosanne 09:22

Well, exactly.

Caitlin Baran 09:23

It's it is it's just most people can't get past that barrier of thinking, you know, it's past this or someone's gonna talk me into something that I that I don't want. I also think that I can sort of closely are intimately intertwined with that is like this idea of giving up, and that if I have this other team on board, and I'm even talking about the future or talking about my options, somehow it means that I don't have hope, or I'm giving up on the treatment, or I'm sort of disavowing what my primary doctor or provider is is doing for me Exactly. It's just not that.

Rosanne 10:02

No. And I think part of that misunderstanding is the people that will say, you know, well, they didn't want to treat my father, they just wanted to push them into palliative care, which is, you know, the medical field will treat you until the very last moment of your life if you want them to, and I think that's part of the bad experiences, kind of get whispered down the lane, and then it becomes this big like, Oh, you don't want that you don't want that. That's just, you know, they're ushering you out here, when really, it's more about empowering your care?

Caitlin Baran 10:33

Totally, totally. It is. It's almost like a self fulfilling prophecy. In some ways, the way that we're stuck right now, you know, people only often do experience the benefits of palliative care towards the end of life. And so they associate it with that. And then they spread that that's kind of, you know, their experience, or, or sort of, as you said, like, oh, they wanted to push them into that. And it was really against someone's wishes. And so it does, it sort of perpetuates that notion of, of it being sort of, against someone's care or against their, their actual desires.

Rosanne 11:06

Yeah, it sounds like it helps more with transitions in that, you know, when you have a disease or you have an especially if it's a terminal disease, but really, any type of chronic long term disease, there's going to be changes, there's going to be those transitional times and it sounds like it would be helpful with that, how, how does that work? How what does it look like to have palliative care on board as part of your caring?

Caitlin Baran 11:31

Yeah, I think the, you know, the beauty of truly what we call early palliative care, which would be, you know, potentially meeting somebody the beginning of their diagnosis, early into dementia, for example, that might look like, you know, getting to know their sort of individual values at that point in time, where are maybe some of their lines in the sand of things that they would say, Wow, gosh, if that was ever how my life looked, that wouldn't be a way that I would want prolong, I wouldn't want more time like that, or that wouldn't be kind of an acceptable quality of life. For me, I'm starting those conversations early, and not having them constantly. But sort of in, in small bites over time, especially as people get more information and have more experiences that might inform those decisions. It's sort of beneficial in a variety of ways is what I would say is, you know, it helps people as individuals plan, it helps people sort of take their worries and transform them into future options, and can get that peace of mind as an individual. I think the other piece is like, just the power it is how powerful it can be for caregivers to actually hear from the person you love, what their values are. And some of this, like, we may already know, you're spending so much time looking after this person, you do learn a lot about them. But to hear them actually verbalize that and talk about it in advance, then as things are changing, healthcare decisions need to be made you have some of that information to go back to and to actually apply. And to have that peace of mind of knowing you're making the right decision on someone's behalf is huge. Absolutely. So you know, I think you spoke about how it can be so helpful for transitions. I think that's right. And I think those transitions can be really subtle over time, right? It's navigating the diagnosis and the grief that comes with that it's beginning to plan for treatment, and what that might look like and how to make sure you're getting the care that you want along the way. It's also trying to figure out, is

treatment working? Does this make sense for me? What are my options over time? And how do I think about navigating those transitions and having all the resources in place to do it? It's beautiful for service in that way to sort of be present all along the way and continually thinking about how do we make sure that the care that this person is getting really actually winds up with what they want?

Rosanne 13:57

Right. Well, and it's interesting, because I would think for something like like kidney disease or congestive heart failure, you start down this path, and then it breaks off into 1000 different paths. And what happens a lot of times is that you're just you're single focused on what's next, what's next. What's next, without the information of everything that could be an option to you. And I think in that world of trying to make decisions, that's where palliative care shines, because then it gives you those options. Is that kind of the idea?

Caitlin Baran 14:33

Totally. I think sometimes it almost feels like you get on the treadmill, and there's not an option. That sort of, okay, well if I, if I start dialysis, this is just what I will do. And then this is how things will look. Or if I continue on these medications for my heart failure, and I need to go to the hospital. That's just what I will keep doing.

Rosanne 14:54

Right. Exactly.

Caitlin Baran 14:56

And you're right, I think there's often not space is to just have a pause and say, How's this going for you? Brain? Is it? Is it sort of a worthwhile balance for you? Are we taking care of you? Well, and if we need to make changes, how could those look? What are the other options? I think you're right. That's where palliative care shines to sort of ask for that pause to make sure everybody has all of the information that they really need to make these difficult decisions. And to think about how we would recommend decisions for people,

Rosanne 15:32

Right. Well, because it's hard to because we don't know. We don't know, as divers, as patients, we don't know, we're just going on what the doctor is telling us. And it's like, okay, we can try this. Okay, we can do this, and you just keep waiting for the next appointment, instead of being able to say, well, what is this? What does this treatment look like, to my life? And what are the options? If I don't like this treatment? What do we do? Like? Do you know what I mean? There's choices and it doesn't, a lot of times, it doesn't feel like you have many choices. It's either you keep going or you stop and you die.

Caitlin Baran 16:08

Totally. And, and gosh, when faced with that second option there, in that presentation of it, like goodness, I would just keep going on that treadmill, many people would exactly. It's scary, and to not have actual space to talk about what what does care look like, because that's the thing, it still is care that you get, even if it's not the treatment that the heart failure specialist is offering, or the cancer doctor is offering, there's still care, but we have to be able to talk to people about what that looks like. Right? I

think it's so true, right? Especially as caregivers, people learn so much, you become experts in some ways about dementia and, and heart failure and all of these diseases. And you know, how it plays out in the lives of individuals more practically than most of the actual health care providers do. Right. And at the same time, that doesn't give you sort of all of the knowledge to know exactly what to expect, and how to think about making those treatment decisions. Right. You know, I think one of the things that palliative care does and can do is to actually talk with people about how to approach that what questions to actually ask of providers, and you know, ideally, it would be great if you had a palliative care provider there with you to do some of this, but also, you know, we can empower people to be able to do it to navigate the healthcare system a bit better.

Rosanne 17:35

No, absolutely. And that's, that's the part like, what what do you ask them? What are the questions? Because it's not, it's not just do you want antibiotics and water? Totally. You know, like, Okay, well, if you're incapacitated, you it's more than that. It's about your life.

Caitlin Baran 17:53

than checkboxes? It is, it is it is let's talk about it. Yes, you know, the thing that I first asked people to do is to think about questions for themselves or with the person that they're caring for. So the first things that I suggest are pausing. And as an individual is thinking about, what am I hoping for, for this treatment? What do I hope the outcomes will be? I'm writing them down all of them. And then I think about, you know, what do I worry about with this treatment? What are the potential downsides of it, or the things that I make me nervous, putting those down on paper seems a little nutty, and it can feel a little intimidating, too. But I think it's a really good check to sort of understand what you're aiming for. And also, it begins to get a little bit of what are the things that might not be okay with me? Or do make me really worried or nervous that I want to talk with my providers about? Then go to the providers? And so how do we do that? Right? All right, I'll name first of all, it's super intimidating. Oftentimes, it feels like right, people have 15 minutes in an office. And so I think, give your provider a heads up that you want to talk about some of this stuff, to sort of think about treatment decisions, thinking about, you know, advanced care planning these pieces together, so that maybe they can slot a little bit more time. But if nothing else, they at least have the heads up and sort of know what, what's coming. And then I think, you know, asking really, really clearly, you know, what is this treatment? And what are the potential benefits of it? And in addition to that going a step further, how likely is it that I'm actually going to experience these benefits? And then the flip side, what are the potential burdens? And you know, I think pushing people on both of these things, the potential benefits being, you know, how days look how much time you get, how you feel all of those pieces, but the potential burdens also being just as complex, you know, does it mean that I am at the hospital four times a week? Does it mean that I feel sick for four days out of seven? Does it mean that I feel sick or only one day out of seven? How does that sort of actually look? And how would I Kalia Maya to experience those burdens, right? So you know asking first about the treatment, sort of the pros and the cons and the likelihood of each of those things. And then, you know, take a deep breath and share with them, actually some of the things that you're hoping for and that you're worried about. And then asking, frankly, like, do you think the treatment is going to get me what I'm hoping for? And if not, is there a different option that you think might align with that? It's tough questions.

Rosanne 20:24

They are. They're really tough questions. Yeah. But they're important questions.

Caitlin Baran 20:28

Totally. And they're completely reasonable questions. Right. And I think the the other things I really encourage people to ask and questions that should be yours are, what should I expect if I don't do this treatment? Yeah, kind of gets at that question of like, what is the flip side? And asking somebody to really talk about that, and knowing they may not have all the answers, but they have some answers, and they can think about it together with you. I will also just name you know, some people want all of this information, and some people don't. And so it's, you know, kind of picking and choosing what works for you. But, you know, taking this sort of question a step further of what to expect that again, could mean What will my days look like? Sort of how will I be able to function? Some people want to know how much time I might have, and then talking about more of the logistical or overarching pieces of like, what does care actually look like? What are the options for in home care for facilities for care if I am nearing the end of my life? What's out there? And then the last question that I always really encourage people to talk about, or to ask of their provider when they're thinking about, you know, making a decision about treatment is, how will I know if it's actually working for me? Sort of what will be the check in point? I think it's, it helps individuals and caregivers then No, to sort of say, Okay, this is my barometer, I'm like, moving in the right direction. I'm not moving in the right direction. And when are we going to actually check in again?

Rosanne 22:01

Right, right. Yeah.

Caitlin Baran 22:02

When will we pause that treadmill for a moment and say, hey, yeah, this is actually like doing exactly what we hoped it would do. And we should keep going on this? Or, oh, it's been a little different than we were hoping and like, Does this make sense? Or do we pivot? And try something different right now? And I think it forces I think your healthcare providers to also think about that question. Like, how will we know?

Rosanne 22:27

Right? No, that's great. Yeah. Because it is, you know, some people want to know, the whole picture. And other people don't want to they don't want to see it at all. Totally. And that's okay. I mean, listen, whatever works for you, works for you.

Caitlin Baran 22:39

It is and what I would say is, you know, sometimes it's helpful for people who don't want the whole picture to have their caregivers or loved ones or other people in their lives, you know, their designated proxy, and hold some of that information for them. It is it's really, it's okay. It's just about how to make sure that all of the team has the information that they need to make good decisions.

Rosanne 23:02

And yeah, and that's, I was gonna say, somebody absolutely has to be in that room. Because you know, when you start getting that type of information, it kind of everything kind of fades out, in and out. None of that waa waa affect.

Caitlin Baran 23:14

Oh, absolutely. I think people hear like, 20% of what is actually said, it's just it's too much, right? Is there anything yeah, having having a partner there with you, whoever that is a partner in your care, to, to process the information to think about questions. And also just know, it's okay to ask these things multiple times. You don't have to hold all of that or get all of it the first time. In fact, really, most providers don't expect that anyone could. It's just too much. So doing it sort of as a staged process is really reasonable.

Rosanne 23:48

And to know that going in, because you know, there's always that you get to the car and go, God, I wish I would have asked that or, you know, it's three in the morning

Caitlin Baran 23:54

Write it down, bring it next time. It's exactly, totally okay. And it happens. I mean, just happens to everybody. There's so many things that come up, and there's so much nuance to it. And then there's just the reality that sometimes the person you're talking to doesn't have the answers, right. Sure. which then brings up more questions, right. And I think writing them down and bringing them back and having sort of all of these conversations be things that occur over time, rather than thinking like I have to get all of the answers in this one sort of conversation and make all of the decisions forever. In this one moment, it's just too much.

Rosanne 24:27

But it feels like that a lot of the time when you're in the medical field because you do you have 10 minutes, you know, eight and a half after you say hello, and you know, you're trying to get everything done at that because trying to call back and get through and then leave a message and then get the call. So that's what we're accustomed to. It feels like with palliative care. It's more like you're sitting at a table and it's like, okay, what are we doing? How about this? Here's another question and it's almost like a real conversation if you will, instead of this. Oh my God, I don't know what I'm doing.

Caitlin Baran 24:59

Yeah, I mean, I think that's exactly how it should be a real conversation over time that is had, you know, when it needs to be had when it's helpful to people, as things are changing over time as more information has gained sort of all of those pieces.

Rosanne 25:16

And I think it's helpful to discuss it in real world examples, and not in 20% of people you did, it's like, I know, no math,

Caitlin Baran 25:24

right? Like, what does that actually mean for me? Right? Do you think this is gonna help for me help me? Or what will actually look like for me?

Rosanne 25:33

Yeah, yeah, it's very interesting. And it's, it's hard, because a lot of the doctors that are faced with the end of life timeframe, they don't have enough training, they don't have sufficient compensation for that. And they're just uncomfortable with discussing death with the emotions that come with all of that. And it's amazing, because it's part of the lifespan. Yeah. And yet, there's not that much in that area, like, you know, why did you choose to become a palliative care doctor of all the specialties you could have chosen? What made you choose that?

Caitlin Baran 26:09

Of all the things? Yeah, I mean, I think it's, it's actually just patient centered care. It's individualized, personalized care, I think going through medical school and training, even initially, I often felt like the health care system can be a bit of a grind on people, folks get lost, it's really hard to navigate, it's hard to know what decisions to make, it's hard to feel like as an individual, you're at the heart of what's going on. And not just sort of stuck in a big system. And I didn't palliative care found the very first specialty where I was like, Oh, this is about actually taking care of individuals and meeting their needs, wherever they are, and really trying to help people actually navigate a healthcare system and make decisions that align with what's important to them. And there is a bit more sort of space and focus to be able to just to do that. Yeah, I think it just opened my eyes to a different side of medicine, out name like in an ideal world, it would just be something that everybody did, right? I think that there are so many sort of constraints within sort of the day to day function of what's asked of all of our providers to be able to do that. But I also think you're right, it wasn't a traditional part of sort of medical training and healthcare training for providers to be able to talk about what's important to people. Medicine, I think, historically has been extremely paternalistic. And then in some ways, I think moved the opposite direction of like deference to patients, which can also be really hard of trying to figure out like, Well, you tell me what you want. Like, I don't know what I want. I'm not the doctor, right. And I feel like modern palliative care actually sort of finds the happy medium, all of that of, you know, patients are the experts in themselves. And providers are the experts in medicine. And ideally, we sort of marry those two things to figure out how we actually take care of an individual. And so I mean, I'm lucky to be able to do this job to get to know people and to help them, you know, actually get the care of it makes sense for who they are.

Rosanne 28:27

No that's beautiful. And because it's so hard, and it's so it almost feels like healthcare has lost the care part has lost that personal care part.

Caitlin Baran 28:39

Yeah.

Rosanne 28:39

And, you know, anytime you're in those situations, you're scared.

Caitlin Baran 28:45

I mean, it's totally overwhelming.

Rosanne 28:47

It's totally overwhelming, and you don't know what to do. And the stakes are high, because it's somebody's life that you're dealing with. Yeah. And it's, you know, it's like showing up for a test you never studied for.

Caitlin Baran 28:57

Yeah, it really is. It really is. And I think the logistical machinery of the healthcare system makes it even more impossible. Yeah, you mentioned like how long you sit on Wait line trying to get through just all of it. If you weren't navigating living with an illness, it would be hard, right? But trying to do it as a caregiver or as somebody who isn't feeling great, or is actually just even trying to process a diagnosis. It's just completely overwhelming.

Rosanne 29:26

And it feels like that can incorporate caregivers better than the quote typical healthcare setting. Do you know we don't get billed for they can't bill for us?

Caitlin Baran 29:36

There is no code for you its true

Rosanne 29:39

No code. So I feel like you know, in my mind, I feel like palliative care kind of like incorporates the caregiver.

Caitlin Baran 29:46

Yeah, I think it absolutely has to, you know, I think that the caregivers hold so much of this. Right. They're able to help process enormous information for individuals there. We're able to give more background information, they're able to talk about some of the logistical things that sometimes are lost to the person who's facing the illness. I also think that they're often collaborators in decision making, they're there for the individual, when the provider is not there anymore, you know, it's the caregiver and the person home trying to figure out like, Okay, well, what are we going to do? And how are we going to figure this out together? And then, you know, it is sometimes actually the caregiver who is making the decisions on behalf of the person. And it's a crazy notion to think that, you know, caregivers, hey, you shouldn't be a part of this until that moment, in the middle of the night when the person can't talk to me anymore. And then I'll call you, and you're the most important person in the world. And I need to speak to you now. And can you make this decision for me, or make this decision with me, it's just not how it should be. There needs to be, as you said, sort of everybody at the table, processing this information together and having these conversations? Yeah. And I think, you know, there's opportunity, even with palliative care for empowering caregivers, and individuals to have those conversations at home to sort of start them in the absence of the health care providers, and to begin some of that, and it sort of better prepares people then to come and talk to the providers. It's also really hard, but it's one of the things that we do, I think we can guide people with tools, and then we can also facilitate the conversations themselves.

Rosanne 31:29

Well, that and that was my very next question, how do we, how do we bridge you know, everybody's uncomfortable about discussing end of life? Or heavy topics or treatments, whatever? How do we bridge that gap? How do we make that happen?

Caitlin Baran 31:44

Totally. It's hard, right? There's so much emphasis on like, wanting to be present and wanting to stay hopeful. And what I would say is, the first thing in your mind you have to hold is that two things can be true, you can hold hope, and you can be present. And you can also take some time and space to talk about some of these things. And so operating under the principles of duality, when I tell people first is, you know, with the person that you want to have the conversation with, so if you're the caregiver, you know, thinking about the person you're caring for, come to them and name but it's hard. You know, I know that you don't want to talk about if you get sicker. I know you don't want to talk about end of life. And I also want to talk about it, because I want to make sure I do right by you. So name, it's hard to sort of share your why whether that's wanting to advocate for the person, whether it's just being worried about them, sometimes, you know, people have actually had experiences that were informative for them in a positive way, or in a negative way. And so thinking about that aunt who went through this thing, and I know that that was really hard for you, or you said that you would never want that, or you were so appreciative of the care that they did get. And so I want to make sure that I honor that wish for you. So after you share your Why make a time and put it on the books, you know, say like I let's let's find a space to do it, you know, over dinner is not always the ideal. So let's find, let's find an hour and put it on the calendar and then sit down and do it. I think that, you know, that's the sort of the easy way to easier way to approach starting the conversation. And then there's the actual sitting down and doing it. I think there's a lot of tools out there to start these conversations. And I think it's really important for people to know that they're not alone. I'll also name that sometimes just having a third party ends up being ultimately what you need. And so if you find you can't get the answers, or it's just getting stuck, it's not because you're doing it wrong. It's just because it's hard. And sometimes you just need somebody else. But I think you know, some questions to start with to ask, you know, the person you're caring for, and you can name you know, i These may seem like silly questions or like you probably think I already know these, but I'm gonna ask them anyways because I want to hear you talk out loud. I want to hear your words from you. That's important to me. Just asking them you know, what brings you joy? What do you feel like it's good in your days? Right now, you know, given given this dementia diagnosis or given where you're at with a heart failure? And then asking them what what are you hoping for? What do you want your days to look like? What are you hoping treatments? Do? What do you want more of cooking, being outside? Just a couple more naps in a day sometimes. And then asking, What are you worried about? Can be a really hard question for people. And so I think there's also space just to acknowledge the emotion of it and simple tools to be able to do that are just saying naming again, it's hard. This is a really hard conversation. And, and also, like I said, I want to do it because I care about you. I think that even naming for people talking about what worries you doesn't mean it's going to come through can be really helpful, but I want to, I want to hear about it. Because I really want to know how you think about it. Right? Some other questions that they can feel harder. And sometimes this is a stage to conversation. But a deep dive question is to say, you know, if time is short, how do you want your care to look? How do you want that time to be as being home important to you? Would you, you

know, want to be in a facility? How do you think about the balance of those things? What else is important, and then trying to get out, you know, there's this person who maybe they've never even shared it out loud, but they might have these lines in the sand, as I alluded to, before, of ways of living, where you would say, I don't actually want more time in that way, or that wouldn't be an acceptable quality of life for me. And that line can be in so many different places for people, but understanding for them as an individual, you know, in this moment, do you have any of those are not really yet. And knowing that sometimes those lines develop through experiences over time, through adapting and sort of knowing how it is to actually need more help? Or how it is to do a treatment sort of informs like, oh, I actually think I might have a line here where I wouldn't want this anymore. If things didn't get better. So those are, those are hard questions. But I think they're a really good start to understanding what's important to people what their values are, and where they would want their care to go. And again, knowing that this is a sort of a conversation that I think people get stuck in sort of saying, like I did that, right? We talked about that. I filled out that advanced directives, you're all set? Can't you just pull that out? And I think it's so important to know, what you might say, in answer to these questions when you are 37, and don't have any illness or aren't navigating anything sort of complicated with your health care, might be totally different than what you say, when you first get a diagnosis, which might be completely different than what you say, as you are needing more help at home. Or as you're getting sicker, or as you hear from doctors that you might be at the end of your life. And so it's just actually completely practical and reasonable to have these conversations over time. To kind of check back in with people.

Rosanne 37:28

Yeah, because as hard as they are to have, it's harder after the fact, if you hadn't had them, and you had to make the decisions yourself.

Caitlin Baran 37:36

Totally, there's so much uncertainty in that, right. And even if you've had them a couple of times, you have some information to provide a groundwork for that decision making, which can give so much peace of mind for caregivers. I think, you know, it's it is hard. And also when you kind of go back to that why it's so powerful, oftentimes, right? You're not doing it because it's malicious, or because you want bad things to happen, or because there's a thrill in talking about this subject. It's really It's because you care, because you want the best for this person. And so I think structuring it, that it's a conversation in sort of a confined space and time that you revisit when you need to, is really helpful. I think that also helps to like contain it for people so it doesn't feel like Oh, are we gonna keep talking about this? again tomorrow?

Rosanne 38:30

Right? No, nobody wants that. Yeah, right. Exactly.

Caitlin Baran 38:32

It's like alright, let's put like a lid back on it. We've like talked about something because I got some really important information. I know how you feel about these couple of things. And like, I will come back to it if things change for you, or if we get more information or whenever we need to, right. But you've done the really hard work of actually just talking about it together.

Rosanne 38:54

It's prep. And it's an it's information. And I always say you know, information is powerful, even if you don't like the information.

Caitlin Baran 39:00

Yeah, it is

Rosanne 39:01

It is you put it out there and whatever you get back is informative. For sure.

Rosanne 39:01

It's powerful

Rosanne 39:05

Exactly. Now, can you come off of palliative care then?

Caitlin Baran 39:10

Absolutely.

Rosanne 39:11

How does that work? Like, what does that look like? Like okay, for right now you have this diagnosis and you're you're doing palliative care. And then it's like the on ramp to hospice, that you sign up for palliative care. And then from palliative care, you go to hospice, like its one and two.

Caitlin Baran 39:24

Do you have to sign up for hospice at the end of it?

Rosanne 39:27

Right. That's the question.

Caitlin Baran 39:28

So what I would say is, you sign up for hospice, when it makes sense for you if it makes sense for you. When it aligns with your goals. What I would say in addition to that is if palliative care is no longer beneficial for you or doesn't align with your goals anymore. It doesn't make sense to do it anymore if you don't need it anymore. People we talk about people graduating from hospice, and people graduate from palliative care as well. Okay. People get cured, they get better. They don't need sort of the support to either get help with symptoms or to navigate these sort of decision making pieces over time anymore. Yeah. It would be such hypocrisy if we told you it was the treadmill you had to get on. And you could never get off.

Rosanne 40:14

That's it. You're stuck. That's it. You're on the you're on the path. Okay. Yeah.

Caitlin Baran 40:18

Palliative care is here to serve really, for however long it makes sense for someone.

Rosanne 40:24

The lack of palliative care doctors, is something that you address with your company. Is that accurate?

Caitlin Baran 40:32

Yeah, so our company at Epione MD is a company that was born out of palliative care to begin with. It's a coaching company for individuals who are navigating aging or illness as well as their caregivers. So my partner, Dr. Ashwini Bapat and myself, came up with this idea. I think first, exactly, as you said, because there's just not enough actual palliative care providers out there. And then there's so many limits on accessibility of it, particularly over diagnosis, duration of sort of time that people can get it, or geographic constraints in rural areas, whatever it is, there's just not enough. And so our question was, how do we bring sort of the benefits of palliative care to more people and actually also serve caregivers in a more direct way. And so born out of that was a Epione MD, which is really focused on helping people who are living with illness, navigate it better, sort of bringing all of the benefits of palliative care and spiritual sort of psychosocial support, help with these conversations about advanced care planning and thinking about making healthcare decisions that align with individual choices. It's also, you know, as you sort of said, for folks who are who are just aging, who they may not have a serious illness diagnosis, and so they are precluded from getting a lot of the actual palliative care that's out there, you know, they might be overall really well, they just want to talk about some of this stuff with somebody, and actually do some planning and think about how to sit down with family members. So we create that round table for them to figure out what's important to them, and started that conversation and start thinking about what documents might be actually helpful for them to have pulled together for family and for caregivers. And then sort of that third piece is the caregiver. You know, we we can see caregivers as clients, it's a totally different model. But being able to provide, again, sort of spiritual and psychosocial support for caregivers, as you're navigating this whole entire journey, and to even help people who are approaching the point where they're having to make decisions on behalf of somebody, or who they're actually in that situation already. To make those decisions. I think it's a bit of a different model. I think coaching is new for people, for sure. But it's really, truly I think the epitome of again, that sort of like personalized care, being able to meet people where they are, and really different. And it's been such a privilege to be able to serve more people than in the traditional palliative care model.

Rosanne 43:20

No doubt, and I'm sure it helps a great number of people because it it brings you back to that. And I you know, I hate to say this, the the the way, it used to be where you were able to have an actual conversation where your doctor didn't know you and have a relationship and understand how you lived and and what was important to you. And that's a part of health care. But we've kind of lost that along the way.

Caitlin Baran 43:45

Totally, I think it's there's just not enough time and space for it. And so we got to do that. And you know, one of the things that we still do at Epione is work together with the healthcare teams. And so we kind of get the luxury of getting to know individuals and figuring out those values and figuring out what they

need and taking that information back to some of their health care providers to be able to lay that out for them. And kind of backfills that story then too. I think when people go and meet with their provider, it's just it makes it a more kind of holistic experience in a roundabout way. Again, sort of working within a system. That's not ideal, but trying to make it a bit better.

Rosanne 44:27

Well, sure. And it's really helpful when you get when you go into the provider with your okay, I've got my plan. And I'm going to ask you these questions. And I am going to, you know, I'm waiting for the response to this to have that to bring that next question forth. And it's helpful because you're prepared.

Caitlin Baran 44:46

Yeah. Yeah. You know, one of the things I actually love doing as a coach is being able to think about like, okay for you as an individual, this is the illness that you're navigating, or this is as a caregiver, what you guys are trying to sort out right now, here are the questions I want you to go in Ask your healthcare provider. And here are some follow up questions and then circle back afterwards. Right. You know, we'll have another follow up session to sort of process through that and think about, okay, you know, what's next? Yeah, it is. It's a strange way in some ways of having to do things. But it's, it's nice. And it really truly does see people feel empowered. Which is great. Yeah. And sometimes it's enough just to actually have those questions and know, you know, I'm gonna march in there. And this is what I'm going to ask. And I'm, I'm totally validating these questions, and they're the questions that I need to know the answers to.

Rosanne 45:35

Right. Right. That's half the battle.

Caitlin Baran 45:37

Totally.

Rosanne 45:37

Anything that's empowering. I'm all in.

Caitlin Baran 45:40

Yeah, yeah. I think the more that we can do to help people to actually navigate the system, the better off we are, it sort of has to be a two pronged approach, like fix the system, but also actually help people in the meantime,

Rosanne 45:52

Right, because it's not going to be fixed overnight. It's not gonna happen tomorrow. No, no, we, but we're still trying to survive within it.

Caitlin Baran 46:00

Yeah, absolutely. Absolutely. I think one of the other pieces that's been fun out of Epione is to create sort of tips and tricks and things for people that are more accessible, like actual just handouts, or free sort of insider guides to navigating the healthcare system to living well. And, you know, I think our

traditional healthcare system doesn't do anything like that. We kind of have to keep it to ourselves, right? It's been a really nice and sort of rewarding part of the work at Epione.

Rosanne 46:33

I would think it would be because it's actual factual information from doctors and not tips that you're getting off of tik tok.

Caitlin Baran 46:40

Yeah.

Rosanne 46:41

You know, like, it's for real,

Caitlin Baran 46:44

It's for real um, it's well informed we like to think and it's helpful for people, I think, if it can be sort of readily applied. And again, it's something that people don't have to dig for or pay for, which is huge.

Rosanne 46:59

And it's all off of your website?

Caitlin Baran 47:00

It is all off of our website. We do monthly blog posts that are all free and accessible there. We actually have a series that just kicked off this week that will be going and available, called the Live Fully Series, helping people navigate common sort of issues that come up when you are facing an illness. And then people can sign up for newsletter to get sort of additional tips and tricks again, sort of all three on Subscribe. It's too burdensome for you. We totally understand. But we do just want to help if we can.

Rosanne 47:35

That's wonderful. That's wonderful. Oh, my goodness. That's great. And that's

Rosanne 47:39

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Rosanne 47:43

No, that's great. I love that. Because it's, it's helpful. I mean, it's just helpful. I mean, I know that sounds silly. But, you know, it's so hard trying to keep all of the balls in the air when you're caring. And when you're dealing with something as stressful and emotional and frightening as a diagnosis of any kind. And to have the ability to find that information is a gift.

Caitlin Baran 48:07

It totally is. I think this is like not just to toot our own horn by any means over here, I think it's to it's truly, you know, it's, you're entitled to it, I guess is what I would say, as someone living with illness and as a caregiver, all of these things should be out there and should be accessible. And we should be supporting people through all of this in better ways.

Rosanne 48:33

Agreed. Totally agree. Any final words that you would want to say to caregivers listening or people that are just beginning this journey going forward?

Caitlin Baran 48:43

I think, to caregivers listening, I think I just wouldn't genuinely express a sense of gratitude. I think that the work that you're doing is so often unseen by the healthcare system. And I will say as a palliative care physician, and as a coach, sort of providing this supportive illness and aging service. I am so deeply grateful, and I see what you're doing. And it's huge. It really is. There's no other better words to sort of say it really.

Rosanne 49:16

A big thank you to Dr. Caitlin Baron for being my guest today. For more information and free resources about palliative care, head to her website, a EpioneMD E P I O N E M D.com. I hope you enjoyed our podcast today, head over to doctor hood.org and click on the podcast section for Show Notes including the full transcript and links to any resources and information from today's episode. You can find and review us on Apple podcasts or anywhere you listen to your podcasts. We are also on Facebook, Twitter, and Instagram. At daughter hood the podcast and Daughterhood the Podcast.com Feel free to leave me a message and let me know what issues you may be facing. And we'd like to hear more about or even if you just want to say hi, I'd love to hear from you. Also a very special thank you to Susan Rowe for our theme music, the instrumental version of her beautiful song mamas eyes from her album Lessons In Love. I hope you found what you were looking for today, information, inspiration or even just a little company. This is Rosanne Corcoran. I hope you'll join me next time in Daughterhood.